INFACT
Joint Action on Health Information

Task 8.1: Generating knowledge on data collection methods, quality assurance, availability and accessibility of health information: a cross-sectional survey across EU/EEA Member States

Milestone 27: Questionnaire for MSs regarding health data collection methods and procedures

Wp 8 - Tools And Methods For Health Information Support

1

TABLE OF CONTENTS

POPULATION HEALTH MONITORING and HEALTH SYSTEM PERFORMANCE ASSESSMENT

1. INVITATION MAIL

Dear colleague,

We would like to invite you to take part in the online survey aimed at identifying health data collection methods and procedures in Member States. This survey is conducted within the framework of the Joint Action on Health Information (InfAct – Information for Action).

InfAct is a 3-year Joint Acion (2018-2021) funded by the European Commission, involving 40 partners in 28 European countries. JA InfAct builds towards a sustainable and solid infrastructure on EU health information and strengthens its core elements based on capacity building, health information tools and political support (see https://www.inf-act.eu/).

The questionnaire asks about data collection methods, quality assurance, and availability and accessibility of health information in your country. The questionnaire can take about 45 minutes.
Before answering, please, read the background document containing important supporting material needed to fill-in the questionnaire and the 'Glossary of terms' at the following link: Background document link: _____

The aim is to identify national data collected of population health monitoring/public health surveillance and health system performance assessment (HSPA). The collected data could be part of European research networks, such as EUROCISS, EHES, ECHIM, EUBIROD, ECHO or purely national data collections. There is no need to report data collections which are already part of existing international databases of WHO, OECD or EUROSTAT. This survey is also an opportunity to identify and describe "isolated" projects/studies, which provide standardized and comparable health data at national level.

The survey is conducted by the Italian National Health Institute, Rome, in close collaboration with partners from the Netherlands, Germany, Slovenia, Finland and Spain.

Your answers will be held in strict confidentiality and used only for the purposes of this study. Should you have any questions regarding the survey, please contact Luigi Palmieri at luigi.palmieri@iss.it or Brigid Unim at brigid.unim@iss.it

Survey link:_____

Please, feel free to share the survey link with your colleagues with good knowledge and experience in health monitoring/public health surveillance and HSPA data in your country (e.g. epidemiologists, researchers that have played leading roles in EU projects, health data managers, etc.).

We thank you for your collaboration!

Luigi Palmieri, InfAct WP8 coordinator

2. INTRODUCTION (Annex 1 in the online version)

InfAct is a joint action (JA) on health information (HI). The major outcome expected from the JA is a sustainable solid infrastructure on EU HI through improving the availability of comparable, robust and policy relevant data on health status and health system performance. Through country collaboration, the JA aims to streamline HI activities, reduce the data collection burden and works for a sustainable and robust data collection in Europe that facilitates and supports country knowledge, health research and policy making.

Nationally, health-related data are collected from a variety of sources such as population-based registries, health interview and examination surveys, longitudinal studies, administrative healthcare records, e-health solutions, etc. Data is collected for different purposes, including population health monitoring (HM)/public health surveillance and health system performance assessment (HSPA). Most of these data are not included in international databases such as WHO, OECD or Eurostat, limiting their use for research and for policy relevant international benchmarking and comparisons.

Health monitoring data provide the main information for the description of population health status. Monitoring is an intermittent or episodic performance and analysis of measurements aimed at detecting changes in the health status of populations or in the physical or social events [1]. On the contrary, surveillance is a continuous process that requires three functions in this sequence: i) data collection; ii) analysis and interpretations; and iii) decision making. The final phase in the surveillance chain is the application of information to health promotion and to disease prevention and control. Public health surveillance is defined here, as the ongoing systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practice, closely integrated to the dissemination of these data to those who need to know and linked to prevention and control [2].

Performance measurement seeks to monitor, evaluate and communicate the extent to which various aspects of the health system meet the key objectives. There is consensus among members of the Committee on the National Quality Report on Health Care Delivery [3] and clinical experts participating in the OECD Health Care Quality Indicator Project [4] that those objectives can be summarized as: i) health conferred on citizens by the health system; ii) responsiveness to individual needs and preferences of patients; iii) financial protection offered by the health system; and iv) productivity of utilization of health resources. A healthcare system should also fulfil other criteria such as equity on access, effectiveness, quality and safety, and allocative efficiency [5].

For health information systems, standardization for data collection for monitoring/surveillance or HSPA is required to ensure comparability of the results. Comparability is often restricted by differences in definitions, used collection methods and tools, and varying uses of classifications. Standardization procedures ensure that three criteria are met: i) the aims of data collection are made explicit and all necessary and pertinent information are collected; ii) data are collected using the same method; iii) the same definitions are used. Standardization is also time efficient and essential for comparing population groups, geographic areas, or trends over long periods of time [6]. Some examples of standardized data collection are: i) Eurostat health statistics are collected from different sources which are under specific regulations [7]; ii) the countries participating in the European Health Examination Surveys (EHES) research network also follow standardized data collection methods and procedures [8]. Standardization of metadata is also important in health information systems describing health data. For example, the main reference metadata-reporting standards used by Eurostat [9] are: i) SIMS (Single Integrated Metadata Structure); ii) ESMS (Euro SDMX Metadata

4

Structure); iii) ESMS-IP (Euro SDMX Metadata Structure – Indicator Profile); and iv) ESQRS (ESS Standard Quality Report Structure). There are also other metadata/data reporting standards facilitating the access and reuse of public information, such as:

- Open archival information system (OAIS), specifies how to maintain, transfer and disseminate archival information across institutions, both metadata and data from public archives. The aim of this reference model is to acknowledge the actors, responsibilities/roles and procedures for the long-term maintenance of archival datasets considered public good [10];
- Data Documentation Initiative (also known as DDI or DDI Metadata), an international standard only for metadata standardization in the case of micro data collected because of official statistics (surveys, questionnaires, etc.) conducted in National Statistics bodies [11].

3. OBJECTIVES

The objectives of this survey are to identify methods of data collection (and the related harmonization and standardization procedures) for HM and HSPA in projects/studies carried out in EU/EEA Member States. These projects/studies **could be part of European research networks** (e.g. EUROCISS, EHES, ECHIM, EUBIROD, ECHO, EuroREACH, EHLEiS, PERISTAT, EuroSafe, euroHOPE, etc.) [12-21], **but the related data or indicators are not included in databases of international organizations** (e.g. WHO-Europe, OECD, Eurostat). Practical examples regarding HM are: i) the Italian health examination survey [22] is included in EHES; ii) the Italian injury data is included in the European Injury Data Base (IDB) [23]; and iii) the Italian perinatal data is included in PERISTAT [24]. An example for HSPA is hospital-specific indicators from administrative databases and medical records in European countries, including Italy, are currently being developed and tested as indicators of system performance (e.g. increased survival rates after acute cardiovascular events, including stroke and AMI) [25].

The sections on availability and accessibility are built taking into account FAIR Data Principles which are a set of guiding principles in order to make data FINDABLE (data and supplementary materials have sufficiently rich metadata and a unique and persistent identifier); ACCESSIBLE (metadata and data are understandable to humans and machines. Data is deposited in a trusted repository); INTEROPERABLE (metadata use a formal, accessible, shared, and broadly applicable language for knowledge representation); and REUSABLE (data and collections have a clear usage licenses and provide accurate information on provenance) [26].

The health data and related metadata indicated by the member states will be described in terms of:

i) Source typology of the information/data sources;
ii) Quality assurance procedures in the methods of data collection;
iii) Availability and coverage (national/subnational) and frequency (the time frequency at which data is collected at regular intervals);
iv) Accessibility.

The results of the survey will be useful in identifying national data collected for population HM/public health surveillance and HSPA with standardized methods that are not incorporated into existing international datasets. This survey is also an opportunity to identify and describe "isolated" projects/studies, which provide standardized and comparable health data at national level. The results will contribute to the development of the European Health Information Platform, a one-stop-shop for EU health information research.

4. GLOSSARY OF TERMS

- **Data:** characteristics or information, usually numerical, that are collected through observations [27]
- **Dataset:** any organized collection of data. The data set lists values for each of the variables and for each member of the dataset [28]
- **Microdata:** consist of sets of records containing information on individual respondents or business entities. To protect the anonymity of respondents (persons, organizations), the access to microdata is restricted [29]
- **Macrodata:** data derived from microdata by statistics on groups or aggregates, such as counts, means, or frequencies [30]
- **Metadata:** explanatory texts documenting statistical data and providing summary information on definitions of populations, objects, variables, the methodology and quality and the statistical production process in general. A distinction is generally made between structural and reference metadata [28]:
  - *Structural metadata* are used to identify, formally describe or retrieve statistical data, such as dimension names, variable names, dictionaries, dataset technical descriptions, dataset locations, keywords for finding data etc. For example, structural metadata refer to the titles of the variables and dimensions of statistical datasets, as well as the units employed, code lists (e.g. for territorial coding), data formats, potential value ranges, time dimensions, value ranges of flags, classifications used, etc.
  - *Reference metadata* (sometimes called explanatory metadata) describe the contents and the quality of the statistical data from a semantic point of view. They include explanatory texts on the context of the statistical data, methodologies for data collection and data aggregation as well as quality and dissemination characteristics

- **Source of information/data sources:** specific datasets, metadata sets, databases or metadata repositories where data or metadata are available. According to the various ways in which data are collected, data sources can be distinguished in administrative, survey and registry sources [30]

- **Quality assurance procedures in data collection/data sources:** Eurostat [31] defines quality of statistical information in terms of the following dimensions or criteria: relevance, accuracy, timeliness and punctuality, comparability, coherence, accessibility and clarity

  - *Relevance* is the degree to which statistics meet current and potential user needs. It refers to whether all statistics that are needed are produced and the extent to which concepts (definitions, classifications etc.) reflect user needs

  - *Accuracy* in the general statistical sense denotes the closeness of computations or estimates to the (unknown) exact or true values

  - *Timeliness* of information reflects the length of time between its availability and the event or phenomenon it describes

  - *Punctuality* refers to the time lag between the release date of data and the target date when it should have been delivered, for instance, with reference to dates announced in some official release calendar, laid down by regulations or previously agreed among partners

  - *Comparability* aims at measuring the impact of differences in applied statistical concepts and measurement tools/procedures when statistics are compared between geographical areas, non-geographical domains, or over time

- *Coherence* of statistics is their adequacy to be reliably combined in different ways and for various uses. When originating from different sources, and in particular from statistical surveys of different nature and/or frequencies, statistics may not be completely coherent in the sense that they may be based on different approaches, classifications and methodological standards

- *Accessibility* refers to the physical conditions under which users can obtain data: where to go, are access to data free or restrictive, etc.

- *Clarity* refers to the data's information environment whether data are accompanied with appropriate documentation and metadata, illustrations such as graphs and maps, whether information on their quality is also available (including limitation in use etc.) and the extent to which additional assistance is provided

- **Other quality dimensions or criteria considered by ECHO are** [32]:
  - *Coverage:* measures the extent to which the sample stored describes actual performance. Also represents a measure of the potential relevance of the data stored.
  - *Internal reliability:* a measure of whether the information stored is consistent over the years. It is a necessary condition for accurate estimations

- **Availability:** availability of micro or macro data, in various formats (publications, files, CD-ROM, Internet, etc.) and documentation related to various aspects of the data, such as methodological documents, summary notes or papers covering concepts, scope, classifications and statistical techniques [31, 33]

- **Remote data access service:** a service providing access to data stored on a computer or network from a remote distance. Remote data access services are often secured to ensure that users can only access data to which they have been approved and that users cannot alter or withdraw/copy the data from the system without permission [34]

- **Health Examination Survey (HES):** population based and objective surveys that provide data on many health indicators to support policy making, preventive activities and research. HES include questionnaire about socio-economic, demographic and health issues, as well as objective physical measurements, such as weight and blood pressure, and collection of biological samples, such as blood or urine [35]

- **Health Interview Survey (HIS):** collection of health status, healthcare use, health determinants and socio-economic background variables of a representative sample of the population living in private households through standardized questionnaires. The European Health Interview Survey (EHIS) includes information from all European Union Member States and is to be conducted every five years. EHIS is used as a data source for important health and social policy indicators such as the European Core Health Indicators (ECHI) [36]

- **Population-based disease registry/register:** in epidemiology, the term register is applied to the file of data concerning all cases of a particular disease or other health-relevant condition in a defined population such that the cases can be related to a population base. With this information, incidence rates can be calculated. If the cases are regularly followed up, information on remission, exacerbation, prevalence, and survival can also be obtained. The register is the actual document and the registry is the system of ongoing registration [37]

- **Hospital-based disease registries** contain data on all patients with a specific type of disease diagnosed and treated at that hospital (e.g. cancer registries). There are two sub-categories under hospital-based registries: single hospital registries and multi-institution registries. The

primary goal of the single hospital (institution) registry is to improve patient care by medical audit-type evaluation of outcomes [38]

- **Drug registries** (e.g. AIFA) record drugs and therapeutic plans submitted to monitoring [39]
- **Medical records** or **clinical data registries (e.g. Healthsearch project, Pedianet project)** contain data on diagnoses, prescriptions and health assessments performed during each encounter with the patient and are recorded as part of the daily practice of physicians [40]
- **Clinical quality registries** (e.g. Sweet project, Pediatric Diabetes 2016) are organizations which systematically monitor the quality (appropriateness and effectiveness) of healthcare, within specific clinical domains, by routinely collecting, analysing and reporting health-related information. They then feed this information back to clinicians to inform clinical practice and decision making [41]
- **Administrative source:** register of units and data associated with an administrative regulation (or group of regulations), viewed as a source of statistical data [28]
- **Survey:** investigation about the characteristics of a given population by means of collecting data from a sample of that population and estimating their characteristics through the systematic use of statistical methodology [28]
- **Longitudinal or cohort study:** observation of the population for a sufficient number of person-years to generate reliable incidence or mortality rates in the population subsets. This generally implies study of a large population, study for a prolonged period (years), or both [37]
- **e-health solutions:** e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a commitment to improve healthcare locally, regionally, and worldwide by using information and communication technologies [42]. Examples of e-health solutions are: i) electronic medical records or electronic health records; mobile health devices (mHealth) collecting survey data, ii) mobile payment processing technology to purchase fruits and vegetables; iii) EATFRESH.ORG is a healthy eating resource that offers multilingual information via its website, social media, and mobile technology; iv) Find MI Care is a free website and mobile application that simplifies the task of finding local, low-cost healthcare [43]
- **Healthcare performance measures**: measures that are commonly used to assess population health in relation to health-care performance. The measures focus on health insurance data as measure of occurrence, disease costs, or on patient data for quality assessment [44]
- **Indicator:** quantitative or qualitative factor or variable that provides a simple and reliable means to measure achievement, to reflect the changes connected to an intervention, or to help assess the performance of a development actor [45]
- **Intermediate linked data source:** a database in which individual information from different sources are linked to contextual information (namely, demographic statistic, socioeconomic data and information on supply) to produce intermediate outputs or data that can further elaborated [32]

5. QUESTIONNAIRE ON DATA COLLECTION METHODS, AND AVAILABILITY AND ACCESSIBILITY OF HEALTH INFORMATION

INFORMED CONSENT

The Participation in this survey is voluntary. You can stop the survey at any time and continue it later. Do you want to participate in this survey?
□ Yes
□ No

The questionnaire should be administered to epidemiologists, researchers that have played leading roles in EU projects, health data managers working in national health and research institutions, and universities.

We will appreciate if you share information on more than one project/study, according to the typologies reported in the Introduction section (e.g. population-based registries, hospital-based disease registries, clinical quality registries, health examination surveys, longitudinal studies, administrative healthcare data, e-health solutions, medical records, etc.). THE QUESTIONNAIRE SHOULD BE FILLED-IN SEPARATELY FOR EACH SPECIFIC PROJECT/STUDY.

5.1 GENERAL CHARACTERISTICS OF RESPONDENTS:

1. Name of the country: _____ (dropdown menu on the online version)

2. Last name of the contact person: _____   First name: _____

3. Type of institute:
□ Public Health Institute   □ Research Institute
□ University   □ National Statistics Department/Institute
□ International Organization   □ Other, please specify _____

4. Work telephone number: _____   5. E-mail: _____@_____

5.2 SOURCE OF INFORMATION/DATA SOURCES - PROJECT/STUDY BACKGROUND INFORMATION

1. What is the name of the project/study: _____
  ➤ **If available, provide a link to the website: _____**

2. Which authority/organization is responsible for this project/study:
_____

3. Who is the contact person for this project/study:
    Name: _____
    E-mail address: _____

4. Which are the main objectives of the project/study (select all that applies)?
□ Health data collection
□ Elaboration of health monitoring indicators (e.g. prevalence, incidence, etc.)
□ Elaboration of health system performance asessment indicators (e.g. hospital-acquired infections, average length of stay, etc.)
□ Standardization and harmonization of methods and procedures
□ Development and/or validation of specific tools
□ Classifications and guiding principles
□ Other, please specify _____

5. What type of health data sources are used (select all that applies)?
        □ Population health examination survey (HES)

  □ Population health interview survey (HIS)
  □ Population-based disease registries
  □ Hospital based registries
  □ Clinical quality registries
  □ Medical record or clinical data registries
  □ e-health solutions (mhealth devices)
  □ Longitudinal or cohort study
  □ Administrative data (e.g. hospital discharge records, mortality, pharmaceutical prescription, etc.)
  □ Electronic medical/health records
  □ Intermediate linked data sources
  □ Other, please specify _____

➢ <mark>(available after each selected item in question 5)</mark> **Please, specify the name of the health data source(s) and, if available, provide a link to the website**

  _____

➢ **Please, specify if the data collection is:**
  □ Continuous
  □ Periodic; please specify the interval _____
  □ Single implementation

6. What type of tools or approaches are used for the health data collection (select all that applies)?
□ Self-administered questionnaires
□ Face-to-face interviews
□ Telephone-based interviews
□ Direct examinations
□ Record linkage of various data sources
□ Electronic medical/health records
□ Mandatory reporting from data providers (i.e., administrative data collection)
□ Other, please specify _____

7. Are health data collected/used by the project/study shared with European research networks (e.g. EUROCISS, EHES, ECHIM, EUBIROD, ECHO, EuroREACH, etc.)?
□ Yes
□ No
□ Under development

➢ **If yes, please specify the research network:**
  □ _____
  □ _____
  □ _____

➢ **If under development, please specify the research network:**
  □ _____
  □ _____
  □ _____

8. How is the project/study funded (select all that applies)?
□ Public
□ Private
□ Other, please specify _____

9. Please specify if the project/study is related to:
□ Health monitoring

□ Health system performance monitoring
□ Health system performance assessment

10. On which of the following main diseases or health topics did the project/study provide information (select all that applies)?
□ Non-communicable diseases (e.g. cardiovascular, cancer, pulmonary, diabetes, etc.)
□ Injuries
□ Unhealthy life styles
□ Mental diseases
□ Perinatal
□ Rare diseases
□ Perceived health
□ Health literacy
□ Health system performance
□ Healthcare utilization
□ Other, please specify _____

11. On which of the following main risk factors, high-risk conditions and health behaviors did the project/study provide information (select all that applies)?
□ Blood pressure
□ Hypertension
□ Lipids
□ Hypercholesterolemia
□ Glycaemia
□ Diabetes
□ BMI
□ Obesity
□ Smoking
□ Alcohol consumption
□ Physical activity
□ Diet
□ Socio-economic factors
□ Environmental risk factors
□ Other, please specify _____

12. Which of the following areas is defined in the project/study protocol (select all that applies):
□ Quality data control
□ Accessibility
□ Availability
□ Analysis
□ Reporting
□ Data linkage
□ Data sharing
□ Other, please specify _____

> ➢ (after each selected item in question 12) **Does the protocol include internationally recognized standardized methods and procedures for the selected areas?**
> □ Yes
> □ No

> ➤ **Please, specify the reference or provide a link to the standardized methods and procedures**
> _____

13. Which are the main indicators elaborated from the collected health data (select all that applies)?
□ Prevalence

□ Incidence

□ Attack rates

□ Performance measures

□ Outcome measures

□ Other, please specify _____

14. What is the main use of the elaborated indicators (select all that applies)?
□ Monitoring

□ Policy planning

□ Research

□ Health services evaluation

□ Other, please specify _____

5.3 QUALITY ASSURANCE PROCEDURES IN DATA COLLECTION

The quality of statistical information is composed of the following dimensions or criteria: relevance, accuracy, timeliness and punctuality, comparability, coherence, accessibility and clarity **(see glossary of terms)** [31].

1. Considering the above definition and the specific project/study indicated in section 5.2 - question 1, which dimensions or criteria are evaluated in quality assurance procedures at the national level (select all that applies)?
□ Relevance

□ Accuracy

□ Timeliness

□ Punctuality

□ Comparability

□ Coherence

□ Accessibility

□ Clarity

□ Coverage

□ Internal reliability

□ Other, please specify _____

□ All above mentioned dimensions or criteria

□ None of the above

2. For each of the selected data sources in section 5.2 - question 5, please provide your opinion/judgment regarding quality assessment of the health data in the table below

Data source 1 (only those datasources selected in section 5.2 - question 5 will be shown)
□ Population health survey (HES)

□ Population health survey (HIS)

□ Population-based disease registries
□ Hospital based registries
□ Clinical quality registries
□ Medical record or clinical data registries
□ e-health solutions (mhealth devices)
□ Longitudinal or cohort study
□ Administrative data (e.g. hospital discharge records, mortality, pharmaceutical prescription, etc.)
□ Electronic medical/health records
□ Intermediate linked data sources
□ Other, please specify _____

Quality assessment criteria	Description*	Highly adequate	Adequate	Present but not adequate	Not adequate at all	Comments
Relevance	Degree to which statistics meet current and potential user needs					
Accuracy	Closeness of computations or estimates to the (unknown) exact or true values					
Timeliness	Length of time between its availability and the event or phenomenon it describes					
Punctuality	Time lag between the release date of data and the target date when it should have been delivered					
Comparability	Measure of the impact of differences between geographical areas, non-geographical domains, or over time					
Coherence	Adequacy to be reliably combined in different ways and for various uses					
Accessibility	Physical conditions under which users can obtain data					
Clarity	Availability of data information (documentation and metadata, illustrations, limitation in use, etc.)					
Coverage	The extent to which the sample stored describes actual performance.					
Internal reliability	A measure of whether the information stored is consistent over the years.					

*See glossary of terms

Data source n……. (If other data sources are indicated in section 5.2)

5.4 AVAILABILITY

1. Are the collected health data stored as micro (individual record) and/or macrodata (aggregated data)?

□ Microdata
□ Macrodata
□ Both

- ➢ **If microdata are available, is there a global unique and eternally persistent identifier (study identifier)?**
  - □ Yes
  - □ No
- ➢ **If macrodata are available, is there an interactive system for users to perform further data aggregation and/or stratification?**
  - □ Yes
  - □ No

2. Which are the available formats of the collected health data (select all that applies)?
- □ Publication(s) (please specify the reference of relevant publication(s) _____)
- □ Electronic files
- □ CD-ROM
- □ Websites (please specify the link _____)

3. Is there a publicly available description of the dataset purpose and content (metadata)?
- □ Yes
- □ No
- ➢ **If yes, do metadata follow reporting standards (e.g. SIMS, ESMS, ESMS-IP, ESQRS, OAIS, DDI described in Introduction section)?**
  - □ Yes
  - □ No
- ➢ **If yes, please provide a web-link(s) to the public information**
  _____

5.5 ACCESSIBILITY

1. Are the collected health data accessible to external users?
- □ Yes
- □ No
- ➢ **If yes, the data are:**
  - □ available to users upon specific request followed by approval
  - □ available to all users without specific request (open access)

2. If access is based on approval, how is it granted (select all that applies)?
- □ By a scientific committee
- □ By an ethics committee
- □ Administrative committee
- □ Legal committee
- □ Formal agreement between institutions
- □ Other (please specify): _____

3. Is there a remote data access service provided for users?
- □ Yes
- □ No
- ➢ **If yes, please provide the website address:** _____

4. Are data reusable (i.e. data have a clear usage licenses and provide accurate information on provenance)?

　□ Yes, for all users

　□ Yes, based on data usage licence (e.g. for a specific project, analysis, period of use, private or public use)

　□ No

5. Is there a financial charge for data access?

　□ Yes

　□ No

We thank you for your participation in this survey.

If you have another project/study to share with us, please click the following link: 'survey link'.

6. REFERENCES

1. Glasziou P, Irwig L, Mant D. Monitoring in chronic disease: a rational approach. BMJ 2005; 330(7492):644-8

2. Teutsch SM, Thacker SB. Planning a public health surveillance system. Epidemiol Bull. 1995; 16(1):1-6

3. Hurtado MP, Swift EK, Corrigan JM (eds). Envisioning the National Health Care Quality report. Washington: National Academies Press (US); 2001

4. Kelley E, Hurst J. Health care quality indicators project conceptual framework paper. Paris: Organisation for Economic Co-operation and Development (Health Working Papers no. 23); 2006

5. Wenzel H. Effectiveness, efficiency and equity. In: Kovacic L, Zaletel-Kragelj L (eds). Management in health care practice. A Handbook for teachers, researchers and health professionals. Hans Jacobs Publishing Company, Zagreb 2008

6. MacDonald PDM. Methods of field epidemiology. Jones & Bartlett Learning, Burlington, 2012

7. Eurostat: methodology. https://ec.europa.eu/eurostat/web/health/methodology

8. European Health Examination Survey: Guidelines for health examination surveys. http://www.ehes.info/manuals.htm#manual

9. EUROSTAT. ESS reference metadata reporting standards. https://ec.europa.eu/eurostat/data/metadata/metadata-structure

10. Open Archival Information System (OAIS). https://www.iso.org/standard/57284.html

11. Data Documentation Initiative. https://www.ddialliance.org/explore-documentation

12. European Cardiovascular Indicators Surveillance Set (EUROCISS). http://www.cuore.iss.it/eurociss/en/project/project.asp

13. European Health Examination Survey (EHES). http://www.ehes.info/

14. European Community Health Indicators Monitoring (ECHIM). http://www.mc3.sk/?projects=echim

15. EUropean Best Information through Regional Outcomes in Diabetes" (EUBIROD). http://www.eubirod.eu/

16. European Collaboration for Healthcare Optimization (ECHO). http://echo-health.eu/

17. EuroREACH. http://www.euroreach.net/

18. The European Life and Health Expectancy Information System (EHLEiS). https://reves.site.ined.fr/en/home/regional_networks/ehleis/

19. European perinatal information system (PERISTAT). https://www.europeristat.com/

20. EuroSafe. http://www.eurosafeimaging.org/projects

21. European Health Care Outcomes, Performance and Efficiency (euroHOPE). http://www.eurohope.info/

22. Osservatorio Epidemiologico Cardiovascolare: Health Examination Survey http://www.cuore.iss.it/eng/factors/oec.asp

23. The European Injury Data Base (IDB). https://ec.europa.eu/health/indicators_data/idb_en

24. Euro-Peristat country teams. https://www.europeristat.com/index.php/our-network/country-teams.html#it

25. Health system performance comparison: An agenda for policy, information and research. Papanicolas I, Smith PC (eds). Open University Press, England, 2013

26. Wilkinson, M. D. et al. (2016). The FAIR Guiding Principles for scientific data management and stewardship. Scientific Data, 3, 160018. doi:10.1038/sdata.2016.18

27. OECD glossary on statistical terms. https://stats.oecd.org/glossary/detail.asp?ID=532

28. Eurostat glossary. http://ec.europa.eu/eurostat/statisticsexplained/index.php/Category:Statistical_concept

29. OECD Glossary of statistical terms. https://stats.oecd.org/glossary/detail.asp?ID=1574

30. OECD: glossary of statistics terms. htpps://stats.oecd.org

31. Eurostat: Standard Quality Report. Methodological Documents, Working Group "Assessment of quality in statistics", Luxembourg, 2-3 October 2003

32. European Collaboration for Healthcare Optimization (ECHO) Project. Zaragoza (Spain): Instituto Aragonés de Ciencias de la Salud - Instituto Investigación Sanitaria Aragón; c2010. Estupiñán Romero FR, Baixauli Pérez C, Bernal-Delgado E on behalf of the ECHO consortium. Handbook on methodology: ECHO information system quality report; 2014

33. SDMX Guidelines. SDMX glossary version 2.0, October 2018. https://sdmx.org/

34. OECD Health Statistics 2018: Frequently Requested Data (Excel file). Glossary of terms. http://www.oecd.org/health/publicationsdocuments/datasets/

35. European Health Examination Survey: National health examination surveys in Europe. http://www.ehes.info/national_hes.htm

36. Eurostat glossary: European health interview survey (EHIS). https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Glossary:European_health_interview_survey_(EHIS)

37. Porta M, Greenland S, Last JM (eds): A Dictionary of Epidemiology. Oxford University Press, Oxford, Fifth edition, 2008

38. National Cancer Institute. SEER training Modules: Hospital-Based Registries. https://training.seer.cancer.gov/registration/types/hospital.html

39. Montilla S, Xoxi E, Russo P, Cicchetti A, Pani L. Monitoring registries at italian medicines agency: fostering access, guaranteeing sustainability. Int J Technol Assess Health Care 2015;31(4):210-3

40. National Quality Registry Network: What is a Clinical Data Registry? https://www.abms.org/media/1358/what-is-a-clinical-data-registry.pdf

41. Australian commission on safety and quality in healthcare. https://www.safetyandquality.gov.au/our-work/information-strategy/clinical-quality-registries/

42. Eysenbach G. What is e-health? J Med Internet Res. 2001; 3(2): e20

43. The Promises and Perils of Digital Strategies in Achieving Health Equity: Workshop Summary. Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities; Board on Population Health and Public Health Practice; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine. Washington (DC): National Academies Press (US); 2016

44. Smith PC, Mossialos E, Papanicolas I, Leatherman S. Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects. WHO Europe/European Observatory on Health Systems and Policies, 2009

45. Glossary of the main terms used in results based management. www.oecd.org/development/peer-reviews/17484948.pdf